

## **HB 6645**

Personal Statement of Ann E. Chambers of 118 Wawecus Hill Road in Bozrah, CT 06334:

The evening before Thanksgiving, 2005, my husband of 25 years blacked out at the top of the stairs and instead of turning right into the bathroom, turned left and fell down a flight of 15 stairs causing severe spinal cord injury. Spinal cord injuries are strange things in that the degree of injury may not be known for 5+- days as swelling either advances or remains at the root of the initial injury. Unfortunately for my patient, the swelling advanced. During a routine MRI, the hospital suggested that we put him on a ventilator temporarily as there was no immediate EMS services available at the MRI site and "just in case" we should prepare for an event; he never came off the respirator. After 1 month in the William W Backus Hospital CCU, he was transferred to Spaulding Rehabilitation Facility in Boston where he spent 2 months. Prior to being discharged, we met with the attending physicians. The diagnosis was a level C-2 spinal cord injury with paralysis to the diaphragm; he would never breath on his own and had a less than 1% chance of ever having any movement in his arms and zero chance of any movement below the arms. He was paralyzed from the neck down.

My patient had Advanced Medical Directives that were executed 10+- years prior to the injury; it was his wish to come home to take time to resolve himself and to convalesce among those things and people he loved the most and who loved him the most. I put my life on hold and did my very best to care and nurture him and I am told by the professionals who monitored him that I did an admirable job. At the end of six months from time of injury, my patient determined that he did not want to continue with life support (respirator, feeding tube, etc.). CT Law defines terminal illness, as "in the absence of artificial life support, the patient will die in a very short period of time". Certainly, the inability to breathe on one's own could be construed by most as a terminal diagnosis.

A Social Worker acting on behalf of the Masonicare Visiting Nurses who was actively engaged in the patient's treatment consulted her Bishop and thus began a long nightmare for the patient and for the family for which we still struggle to recover. CT Statutes provide cover for families of critically ill patients who are mentally incapacitated and those that render services on their behalf; the statutes are silent as to what happens when the patient is critical but mentally capable. In short, had my patient been mentally incapacitated, the law would allow me to disconnect life support and would have indemnified all whom medical professionals who assisted in this effort. Not so for the mentally competent. The family spent \$10,000 in legal fees, consultant fees to Clinical Psychologists who rendered the patient competent, not clinically depressed and clearly understanding of the repercussions of his action(s). In the end, we discontinued life support without the assistance of any professionals.

I would like to speak for those that do not have the \$10,000 to use to enforce the advance directive of their loved ones. I appreciate the position of the Catholic Church and their supporters and fully expect that they have the right and obligation to enforce their beliefs on their membership. However, according to the 2012 Census, there were 313 million people in the United States of which 59 million were Roman Catholic, a percentage, I believe of 18.85%, meaning that more than 80% of the US population in 2012 was something else. My patient was Lutheran, I am a Congregationalist, both his Pastor and my Minister were fully engaged in everything that we did and contemplated from the time of injury until burial and they were fully supportive of his decision.

The right to make life or death decisions is part of one's Manifest Destiny and should not be undertaken lightly and should not be unduly interfered with by those who do not have a personal or advisory position with the patient.

I fully support the Death With Dignity Act and am proud to have provided this testimony.